



"It's not who I am": children's experiences of growing up with a long-term condition in England, Australia and New Zealand.

Journal:	<i>Journal for Specialists in Pediatric Nursing</i>
Manuscript ID	JSPN-OM-17-042.R2
Manuscript Type:	Original Manuscript

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“It’s not who I am”: children’s experiences of growing up with a long-term condition in England, Australia and New Zealand.

Most evidence relating to the experience of growing up with a long-term condition and the impact this may have on a child’s expected developmental trajectory (Venning, Elliott, Wilson, & Kettler, 2008) is quantitative and addresses the perspectives of older children and adolescents (e.g., Smith, Taylor, Newbould, & Keady, 2008) with diabetes, asthma, cystic fibrosis and rheumatic conditions (see for example, Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2015; Jessup & Parkinson, 2010; Jonsson, Egmar, Hallner, & Kull, 2014; [REDACTED]). The impact and influence of a long-term condition on adolescents tend to be reported in terms of the young people’s resilience and how the young people adjust to and aim for control over the disruption associated with the condition (Cartwright et al., 2105; Ferguson & Walker, 2014; Tong, Jones, Craig, & Singh-Grewal, 2012). However, positive affirmatory (Nicholas, Picone, & Selkirk, 2011), resourceful (Cartwright et al., 2105), and mastery (Heaton, Räisänen, & Salinas, 2016) responses to chronic illness have to be seen in the context of the challenges that the young people face (Venning et al., 2008). These challenges include feelings of vulnerability and isolation (Nicholas et al., 2011), difficulties in sustaining friendships (Taylor, Gibson, & Franck, 2008), managing the burden of the illness (LeBovidge, Lavigne, Donenberg, & Miller, 2003) and threats to a young person’s self-esteem (Pinquart, 2013).

The views of younger children are sparse, even in studies where young children were eligible to participate. Reasons for this include methodological issues [REDACTED] [REDACTED] sampling constraints (Marshall et al, 2009; Stewart, Masuda, Letourneau, Anderson, & McGhan, 2011) and service-driven reasons (Lindsay, Kingsnorth, & Hamdani, 2011). The lack of focus on children in middle childhood

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(age 6-12 years) means that there is less contemporary, robust knowledge about how children in middle childhood experience long-term conditions. Where studies have focused on this age group, findings suggest that children acknowledge the constraints and challenges that the condition and its associated treatment bring to their lives such as hospitalization (da Nóbrega, Collet, Gomes, de Holanda, & de Araújo, 2010), boredom, disruption to friendships and attendance at school (Sartain, Clarke, & Heyman, 2000) and the experience of stigma and insecurity (da Nóbrega et al., 2010; Sparapani, Jacob, & Nascimento, 2015). Studies generating empirical data on children's experiences of long-term conditions across different illness experiences, different countries, and within different health care settings are almost non-existent. This study aimed to address this deficit by exploring children's experiences across settings, diagnoses and countries and situating the children as central agents in how they perceive their lives.

The aim of this study was to explore children's (age 6-12 years) perceptions and understandings of how their lives are shaped (or not) by the condition and its associated management.

Methods

Procedure

A qualitative, participatory methodology using auto driven photo-elicitation interviews with the children was adopted to allow us to construct inductively derived understandings grounded in the children's experiences.

Auto driven photo-elicitation interviews, whereby the participant takes photographs to trigger dialogue within subsequent interview (Harper, 2002; Jorgenson & Sullivan, 2009; Schänzel & Smith, 2011) were selected as we aimed to provide the children the opportunity to be able to be visually expressive, creative and able to frame facets of their lives (Kullman, 2012) whilst also shifting the balance of control over data generation from ourselves as adults

towards the child [REDACTED] Children were given a digital camera, an ‘information sheet on taking photographs’ that included guidance on photographic etiquette and broad suggestions of the ‘things’ they might wish to photograph (see Box 1, for summary of guidance). Broadly we asked them to take photographs they thought were important and that would tell us about the illness that they had. We guided the children to take about 20 photographs although we explained they could take more if they wanted to but that we would probably only be able to talk about 20 photographs in total. The children kept the cameras for a negotiated period of time (approximately three weeks) to fit around their activities and commitments enabling them to take a range of photographs before we returned to interview them. With support from his/her parent(s), each child had full control over which photographs were taken, shared with the researcher and retained for use in the study.

The child’s selection of photographs triggered the dialogue between the researcher and the child during the audio-recorded interviews. If necessary, the researcher asked additional questions to facilitate insight into the child’s particular experiences and give the child the chance to talk about situations they would have liked to have photographed but did not for whatever reason. The interviews usually took place in the child’s home as this tends to result in the least disruption to family routine and is the place where the child feels most comfortable and confident. However, two were undertaken whilst the child was in attending an outpatient clinic and one whilst the child was receiving day-case treatment. Again this respected the children’s and parents’ wishes to manage disruption and although these interviews were conducted in a clinical setting, the child was not acutely ill, was familiar with the setting and the setting did not seem to constrain their engagement. The children, in negotiation with their parents, were given the option of being interviewed with or without their parent present. Even when the child was being interviewed on their own (without parental input), there was a parental presence in the background in an adjoining room. Each

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situation was slightly different, some children wanted a parent to be present, whereas others exercised their agency by choosing to tell their story without parental direction. All team members were involved in undertaking the interviews.

Ethics approval was obtained for all three countries taking into account the necessary cultural considerations as appropriate. Clear guidance was developed about the taking of and use of photographs. Robust approaches were used to ensure that the children understood what they were assenting to and could indicate (at any point) if they wished to pause or stop the interview or withdraw from the study. Parental consent and children's assent were obtained and specifically addressed the use of quotations and images in papers, conferences and other forms of dissemination. We adopted a highly reflexive approach to our engagement with children, with ongoing consideration of how the children might perceive our identity, as suggested by Davies (2008).

Recruitment and inclusion criteria

We aimed to purposively recruit 45 children (15 each from England, New Zealand and Australia). Children were eligible to participate if they were aged 6-12 years, could verbally communicate and had been diagnosed for at least 6 months with a long-term health condition that required daily/frequent management by medication and/or interventions. Children were sought from different diagnostic groups and identified by clinical staff working within an acute or ambulatory setting or via community based support groups. In reality, our recruitment was somewhat opportunistic reflecting which children met the inclusion and exclusion criteria and were available during the study period and lived within a reasonable distance from the recruitment setting for the researcher to travel to and from the child's home. The recruitment also reflected the local caseload and support from the clinical staff. We were not aiming to recruit matched samples across the settings.

Analysis

Fieldwork notes and initial analytical impressions were made after each data collection episode by each individual researcher. Thematic analysis (Braun & Clarke, 2006) of the verbatim transcribed interviews, underpinned by the principles of interpretive description (Thorne, 2008) was undertaken. Preliminary analysis of datasets occurred within each country with each team member having primary responsibility for coding the transcripts associated with their own interviews before also coding the other interviews. These preliminary codes and concepts were then shared with the other in-country team members until preliminary consensus was achieved. Extracts of the interviews were shared across the three countries and the within-country codes and themes were shared, compared and challenged via a face-to-face meeting and via Skype meetings until a final shared set of codes and themes was agreed between the three national teams and applied to the whole dataset. This took several iterations until it was agreed that the findings fully reflected the children’s experiences. All authors contributed to the analysis, development of themes and synthesis of the findings.

Analysis of the photographs was limited to a content analysis of what was overtly being presented (e.g., a dog, children playing sport, medals for achievement) although we also considered the photographs and the text in context. These data are not presented in depth in this paper. Quotes are labelled as follows: Eng (England), NZ (New Zealand), Aus (Australia); B (Boy), G (Girl); age (yrs).

Findings

Twenty two boys and 23 girls (n=45), aged 6-12 years, from different cultural backgrounds and from different diagnostic groups participated (Figures 1 and 2). The

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interviews lasted between 15 minutes and about 50 minutes (although some interviews had breaks within this time). The technical quality of the photographs varied from staged images to blurry snapshots. Some existing photographs were included (e.g. grandmother who had died). The children had taken most of the photographs, although some children directed other people to capture events they could not take themselves (e.g., in ambulance on way to hospital or self-administering their treatment). Overall, the children were keen and enjoyed talking about the photographs and they moved past photographs they did not want to talk about, including some images that parents had suggested. **Mostly these skipped images were medically oriented ones (e.g., medicines, hospital) that the children reported had been directed by a parent (e.g., “mum thought this would be a good photo”); the children who skipped parent-suggested images moved onto images that were more important to them and these often included similar photographs that they had taken “without being nagged!”**

One over-arching theme – “It’s not who I am...” (but it’s part of me) - was generated and underpinned by three sub-themes: getting on with my life; the special value of family, friendship, support and comfort; and things that get in the way of getting on (Table 1).

“It’s not who I am...” (but it’s part of me)

There seemed to be a strong call from the children, across all three countries, for them to be seen as a unique but “normal” child, explaining that their diagnosis “*is part of me*” but not accepting that it defined them. Their focus was on “*me as a unique person*” and the condition was typically portrayed as only “*a thing out of many other things*” (NZ-G12yrs). The children were active agents in their own lives as evidenced in the ways in which they **kept the condition in the background and concentrated on living a “real life” with “normal things” in the foreground.** This was evident across the boys and the girls. For the most part, the children’s photographs projected them as engaging in the usual activities of childhood along with their family and friends. Most of the children reported that the condition did not

make much difference to their lives, as one boy explained:

if it was on the scale of a hundred percent, I'd say about ten or twenty percent. Yes I don't think it's that much (Eng-B11yrs).

The children often downplayed the condition, framing it as “*not really big at all*” (Eng-G10yrs) and something they did not worry about too much, although it was clearly something that remained in the background. Many of the children resisted their parents’ efforts to keep them safe or “*wrap me up in bubble wrap*” (Aus-B12yrs); this occurred even in the children who were clearly aware of the seriousness of the underlying condition (e.g., haemophilia, anaphylaxis). Some children were future oriented and talked of how they planned “*to get better*” (Eng-G11yrs) or to “*get fitter*” (Eng-B12yrs) and others envisaged that the future would mean more responsibility for and control over the condition and treatments and less involvement from parents.

Getting on with my life and fitting in

The children were all, to a greater or lesser degree, actively getting as much out of their lives as possible and their parents supported them in this endeavour. Their lives were embedded within a medley of activities, connections and relationships and milestones. The “getting on” photographs projected images of the children as “well” (actively engaging as far as possible in the usual activities of childhood) rather than “sick” children (requiring treatment and intervention).

Sport and other activities. Sport, other activities and having fun were strong elements in the children’s descriptions of their lives and they talked of keeping active (see Figure 3) and doing sport “*taking their mind off things and stopping you get square eyes*” (Eng-G12yrs). The children emphasised what they could do and often presented in terms of the things they can still do (in spite of the condition) as well, if not better, than other children, for example, “*I love playing netball...it's fun. And winning*” (NZ-G11yrs). This emphasis was

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evident in everyday life although there were some more exceptional examples of fitness such as the boy who talked of leading a “*group of people on a bushwalk up a mountain*” (Aus-B12yrs) after he got home following surgery. Other children talked of being encouraged to play sport by their doctor, “[*playing football*] *helps me to get rid of gunge...(it’s like snot)!*” (Eng-B11yrs).

The children’s activities were sometimes influenced by the condition, for example, a child with asthma explained that “[*riding my bike*] *helps my asthma sometimes. ...easier than running*” (Eng-G12yrs). Other children had to take care or “*watch out*” when they were playing, as one boy with haemophilia explained:

I need to be careful with contact, ‘cause I’ll bleed easily and internal bleeding could lead to death (Aus-B12yrs).

The children also enjoyed quieter activities as one child explained, “*I love drawing and I always want to be artist*” (NZ-G9yrs). Some children talked about using social media to stay in touch with their friends or to reach out to other people, for example, “*I posted like this singing video on Facebook and got like loads of likes and everybody said it was like, really good*” (NZ-G11yrs). Other children talked of enjoying board games, playing on their Xbox or computer, shopping, knitting, music and films.

This is my condition and what I have to do (to stay well). The children demonstrated different levels of understanding (ranging from was demonstrably well informed to poorly informed) about the condition; some of this attributable to their age but also their level of experience of living with a long-term condition. The children had gained information mostly from their parents “*nurses explained it to my Mum, my Mum explained it to me and then I got it in my head*” (Aus-B9yrs), whilst others had been active in finding information from books and online:

...when I was like ten I started like finding out more information about it.... I had to

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like choose which information I used because it was like quite dense. Not especially child friendly like some stuff is readable obviously but it's not something they cater for (NZ-G12yrs)

The children were able to describe the procedures and activities required to manage the condition and many recalled times when treatments such as blood tests had been harder to deal with, for example: *"I don't normally cry now but it does really hurt"* (Aus-B9yrs).

Some had an apparently encyclopedic knowledge of their medications, as one child explained:

Prednisolone, Valganciclovir, Mycophenolate, Irbesartan and Tacro – Tacrolimus. Some help my blood pressure. Some stops infections getting to my kidney, or throat, or stuff (Aus-G12yrs)

Mostly the children's descriptions of contemporary treatment were presented in a very mechanistic way: *"She [mother] ... pushes the juice into a needle that goes into my stomach"* (NZ-B12yrs). Their treatments were often incorporated as part of their daily routine (see Figure 4) and even the youngest children were aware of this, *"Those are my medicines. And my second medicine. They keep me very well. I take it every morning when I wake up and finish my breakfast"* (NZ-G7yrs). Overall, there seemed to be a general acceptance that this was *"part of their life"*, as one child explained when describing their *"milk pump"*:

That's my line with my pump milk, which is very gross.Every night for like I think 600 mls. Every Saturday I have it off. But every other night it's the same, I have to have it on. – If I don't have it I could lose lots of weight very easily, and my mum would not be happy (Aus-G10yrs).

The children were not only aware of what their treatment entailed in terms of the medicines, routines and the need to comply with the interventions some were also aware of

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the risks associated with their treatment, for example, the risks associated with injecting “an air bubble” that could result in the child getting “very very sick” (NZ-B8yrs).

However, not all the children were able to provide explanations about the risks associated with their treatment.

The special value of family, friendship, support and comfort

All of the children took photographs of their family, friends and pets who were part of a backdrop of support, comfort and companionship. They were there when the children were well and able to get on with life, and their presence was even more important during times of illness, new treatments and changes to the children’s condition.

Family. The children looked to their family to help them manage their treatments, to understand and support them when they were ill and to make them feel safe, comforted and less ill. Both mothers and fathers had a key role in helping. One boy explained that his “mum helps with pretty much everything” (Aus-B12yrs), and other children talked of the important role of their father, for example who “helps me with my asthma” (Eng-G12yrs) and “helps me do my catheters and gets my medicine ready” (Aus-B7yrs). Children gained support from their siblings who were often described as being “so special to me” (Aus-B10yrs) or who were also sometimes annoying:

it's like she sometimes she helps and sometimes she doesn't like when it's hurting and stuff she like just comes in my room and then, it's like just makes me feel like nothing's happened...like nothing hurts (Eng-G10yrs).

Special support came from grandparents who were often present in the children’s lives and helped to make “me happy when I’m sick” (NZ-G7yrs).

Friends. Some children refrained from telling their friends about the condition as they were concerned about “people treating me differently just because I have a disease or something” (NZ-G11yrs). Others were reticent about talking too obviously about the

condition and casually slipped “clinical talk” into other activities:

“I only talk to friends about hospitals when I’m doing things like handstands” (Eng-G11yrs).

When children did tell their friends they made sure that these were “good” friends who “understood them” and who would intervene if they were being “picked on” (Eng-B11yrs).

Pets, toys and comfort. Almost all of the children shared photographs of their toys and pets (real or toy pets) and these appeared to provide an unconditional level of comfort, closeness and support to the children, for example:

...when I am taking out my [gastrostomy] plug and changing it, I’ll usually hold her paw and stroke her fur (Aus-G10yrs).

Where a child’s condition or family circumstances meant they could not have a real pet, toy pets helped, for example, “*Iggy’s a cute fluffy [toy] bunny ...Iggy helps with medicines*” (Eng-B11yrs). Comfort also came in the form of cosiness such as blankets and comfortable chairs that helped the children feel “cuddled up”. Toys and technology became an important means of comfort, distraction and filled up the less active time. One child explained the value of watching the television:

I think it is really important if you are really sore...you can take your mind off the pain by watching something (NZ-G11yrs).

Whilst this enforced quiet time was not usually welcomed, some of the children sought quiet time as a way of calming them when they were anxious, for example, “*When my asthma’s bad I read a book and ... sometimes that calms me down*” (Eng-G12yrs).

Things that get in the way of getting on

The children talked about how the condition sometimes got in the way and made them feel different to their healthy peers; their lives were more disrupted, restricted and needed

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more planning than other children's. Some of their photographs reflected environments (hospitals, wards, clinics) (see Figure 5) and the paraphernalia of illness and intervention (syringes, tablets, tubing).

Feeling restricted and extra-protected. Some of the children talked about how the condition imposed restrictions that they could not overcome, *"I get tired really easily"* (Eng-B12yrs) meaning they had to spend time resting. Dietary restrictions imposed limits and made some children feel excluded as it was harder to eat out or go to parties, although occasionally these restrictions brought benefits such as *"I got one whole pizza because it's gluten-free"* (Eng-G10yrs). Other limitations included a stronger sense of regimented time needed for treatments as one boy described: *"When I sleep in, that kind of stuffs it up with ... the timing of the insulin"* (Aus-B9yrs). Sometimes children felt their parents were overly protective. Other children worried about the condition and the restrictions this imposed on them and some remembered the things they used to do before they needed treatment. Sometimes the technology, equipment, scars or hair loss associated with treatment restricted the child as it influenced their body image and made them feel less confident in themselves, for example, *"I feel like with my ribs being so big....it just feels uncomfortable to me so for a lot of tops I can't wear them"* (NZ-G11yrs).

Getting/being ill and hospital time. When the children were ill, life became more constrained and there was a shift from active, energetic and often outdoor activities with siblings and friends to less active, quiet, indoor activities such as drawing, watching television and reading. Hospital was a place they did not want to be as it involved additional interventions and "hospital time" was often described as being *"dull and boring"* (Eng-G11yrs) and was time when they were *"getting behind"* at school or missing out on *"being part of things"*. They also had to deal with procedures and their aftermath, for example *"feeling tired"* and not going to *"school when I have my port accessed"* (Aus-G6yrs). Acute

exacerbations of illness were often frightening and disorientating and these were episodes that were “*marked in my head*” (Aus-G12yrs) for some children. Coming home from long admissions to hospital was a big event for the children and some children shared pictures of looking happy and waving goodbye to the staff and the ward; one child commented “*that’s me happy*” (Eng-B11yrs). There was a sense that time moved more slowly and “dragged” when they were ill and/or in hospital.

Discussion

Across all ages and across the three countries the children actively projected their self-concept as “well” children and they strove, through their photographs and their accompanying explanations of their lives, to emphasise that they were “normal” children. The first photographs that the children selected to share with us were of friends, family, pets and sporting and social activities. These active, engaged and vibrant photographs set the scene for our conversations with the children. The children literally showed us the people, places and events they thought most clearly portrayed “this is me”. They positively positioned themselves within the usual concerns of childhood, presenting the same sorts of goals and attending to the same everyday activities and happenings as their friends, siblings and other family members. They were averse to being perceived to be different and were concerned to demonstrate their ability to fit in and get on with things. The children demonstrated that they were active social agents demonstrating their capacity to shape parts of their lives interdependently with their parents and the requirements of their condition (Stoecklin, 2013) in order to fit in. In this respect, their concerns with “being normal” align with findings about the preoccupations of adolescents living with a long-term condition who also strive for normality (Cartwright et al., 2015; Nicholas et al., 2011; Taylor et al., 2008). Part of the way in which the children were able to project this sense of normality was through using their agency and their discretion about whom they told about the condition. Concern about the

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3 stigma of a long-term condition was less overt in the conversations the children had with us
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5 than is apparent in the literature on adolescents with a long-term condition, where stigma
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7 seems to be more problematic (Cartwright et al., 2015).
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10 Underpinning their determination to be a “normal kid” there was also an almost silent
11 use of the conjunctive “but” in their conversations. Their identity as a “normal child” was
12 bound to their identity as a child with a long-term condition. There was a sense of
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14 qualification to their descriptions of their lives; “it’s not who I am” but it is part of me, and
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16 “getting on with my life” in spite of the condition. However, when compared with the reports
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18 of the negative impacts that living with a long-term condition has on adolescents, especially
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20 older adolescents (Pinquart, 2013; Taylor et al., 2008), this impact appeared to be more
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22 muted in the children we talked to. The children did not appear to ruminate on the condition
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24 in the same way that some adolescents have been shown to (Garnefski, Koopman, Kraaij, &
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26 ten Cate, 2009). They rarely talked of feeling miserable as might be expected considering the
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28 work undertaken in children and adolescents that identifies that children and adolescents with
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30 a chronic health condition can experience higher levels of depressive symptoms and
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32 psychological distress compared with their health peers (Denny et al., 2014; Pinquart & Shen,
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34 2011). They appeared able to incorporate the condition into a fairly robust sense of self, as
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36 also seen in studies that have identified adolescents’ resilience, acceptance and self-growth
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38 (Cartwright et al., 2015). This apparent acceptance of the condition and its incorporation into
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40 their lives is somewhat different to other findings from older children who often frame the
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42 condition as being unwanted (Venning et al., 2008). The children were “doers” and agentic
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44 within their own lives looking for solutions and had a determination to “be happy”. The
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46 children seemed, for the most part and for most of the time, adaptable, learned from their
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48 experiences, had a strong sense of self-worth and were resilient. The resilience they
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50 demonstrated was “achieved by virtue of the child’s abilities, motivations, and support
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3 systems” (Condly, 2006, p. 213) and was dynamic in that they were not resilient all the time
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5 and in all circumstances (Kolar, 2011). It was clear from the children’s conversations and
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7 photographs that they were not resilient all the time and in all circumstances and their
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9 positivity shifted in response to how stable or disruptive the condition and/or treatment was.
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11 The children were generally well connected and supported in terms of family relationships,
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13 friends and social and emotional support. This sense of connection and the comfort given by
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15 family, friends and pets during times when they were finding it hard to deal with the
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17 condition was an essential component in bolstering their ability to be resilient. The
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19 importance of affirmatory social support is evident in other studies of children and
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21 adolescents with a long-term condition (Nicholas et al., 2011).
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25 Evident throughout the findings was an awareness of time and place. Time moved
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27 differently for the children depending on whether the condition was intruding on their lives;
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29 “ill time” and “hospital time” moved more slowly than “well time” spent with friends and
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31 family. When situations were adverse, the children all looked forward to being well, home
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33 from hospital, engaging with friends and “being me again”; in this sense they were looking
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35 forward to having a more coherent sense of self. Although the children did report times when
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37 they were disconnected from the lives they wanted to live, as seen in other studies (Nicholas
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39 et al., 2011) this disconnection appeared to be transitory. The children were, to different
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41 degrees, oriented to the future when they would have more control over the condition, and
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43 some were hopeful that a cure would be found, suggesting that “being me” without the
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45 condition might be preferable. None of the children talked about the future in an uncertain
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47 way; many knew of the risks associated with the condition and that they had to be careful and
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49 look after themselves. Some were aware of potential death and they seemed to minimize this.
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54 Having a long-term condition meant that the children spent time in places such as
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56 hospitals and clinics that their peers would not routinely access and even everyday places
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were made different by the paraphernalia of illness such as injections, special diets, and nebulizers. Apart from during times of adversity, the condition was managed without much disruption within everyday life, albeit that their everyday routines were expanded to incorporate interventions and treatment. Most of the children took this in their stride and had either developed expertise in aspects of their self-management (e.g. a 7 year old boy who could self-catheterise), and/ or had developed the emotional maturity in accepting treatment (e.g., routine painful interventions). Despite their resilience and their ability to incorporate the condition within their self-concept, there was a sense of compartmentalization at times; friends they talked to about the condition and friends they did not share with, places that they went to as a “normal” child and places they went to because of the condition, things that happened because of the condition that did not happen for their peers. This compartmentalization and non-disclosure of their condition is also evident in findings from other studies of children and adolescents (Barned, Stinzi, Mack, & O'Doherty, 2016; Kaushansky, Cox, Dodson, McNeeley, Kumar, & Iverson, 2017).

Strengths and Limitations of the Study

A key strength of this international study is its focus on the children's experiences regardless of their diagnostic group. Another core strength is that our selection of PEI allowed us to genuinely follow the children's data and concentrate on the things that the children had selected as being important. However, some children were less engaged with the process of PEI and in a couple of cases we sensed that parents had been very active in directing the photography and this had seemed to undermine the child's confidence in the photographs they had taken. Although not purposively seeking resilient children, our sample appeared to be children who were well supported, actively “getting on with it”, were also very interested in sport and were, for the most part, reasonably well during the period of data

collection. Therefore, our findings need to be considered within this context. The method used had some beneficial effects for the children, for example one mother explained that her son’s interest in his medications and treatments had been stimulated by his involvement and he had requested that his mother help him explain his condition to his class.

Conclusion

This study has demonstrated insights in the children’s experiences of long-term conditions and reflects a level of understanding of the things that are important to them and particularly the importance of “getting on” and ‘fitting in”. The children displayed quite a sophisticated understanding of a life both lived and somewhat constricted by a long-term condition but more than this they presented themselves as children who would not be limited by the condition, confirming that the condition is “not who I am”. The findings have implications for nurses and health professionals working with children with a chronic health condition. These are to engage in conversations with the children in order to better recognize their skills, knowledge and strengths, to find ways of promoting their resilience and tailoring care to helps prioritize those activities that are importance to them “getting on” and ‘fitting in”. As Zeiglet and Nelms (2009) noted nurses should shift from an illness-oriented to a normalization paradigm.

Financial support

Financial support was provided through small charitable grants from each of the three countries (Tasmania, School of Nursing and Midwifery, Faculty of Health Science, University of Tasmania. Internal Funding Scheme (no reference number); New Zealand, Faculty of Health and Environmental Sciences AUT Contestable Research Fund (FHES) – grant-in-aid (reference 09/13); England, Alder Hey Children’s Hospital, CNRU funding (no

reference number). The funding sources had no role in the study design, the collection, analysis and interpretation of data, in the writing of the report or article or the decision to submit the article for publication.

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Box 1: Guidelines for children about taking photographs

Thank you for agreeing to take some photos so we can understand about how having a chronic illness makes you feel and how it affects your life.

Please take photos of what you think is important, we want to know what YOU think!

Some things you could take photographs of

- Things you have to do because you have a chronic illness
- Things that seem different because of your illness
- People who help and things that help you
- Anything or anyone else you think we need to know about

Things to remember

- We are looking forward to seeing your photos but please make sure that anyone you take a photograph of (who isn't part of our project and who hasn't given us written consent) knows you are taking their photo. If you are not sure about whether you should take a photo, check with your mum or dad.
- Only take photos of things you want to share with us.
- There are some places that have special rules about not taking photos. So please do not take photos in the hospital, at school unless your head teacher has said it OK, or at the swimming pool.
- You can delete any photos you don't like or don't want to share with us before you give back the camera.

AND If you have any questions or if you are worried about anything to do with the photos, then please contact Bernie or Lucy via the details on the Information Sheet.

Table 1: Overview of themes

Overarching theme	Sub Theme	Sub-sub themes
'It's not who I am...' (but it's part of me)	Getting on with my life	<ul style="list-style-type: none">• Sport and other activities• This is my condition and what I have to do (to stay well)
	The special value of family, friendship, support and comfort	<ul style="list-style-type: none">• Family• Friends• Pets and toys
	Things that get in the way of getting on	<ul style="list-style-type: none">• Getting /being ill• Going to/being in hospital

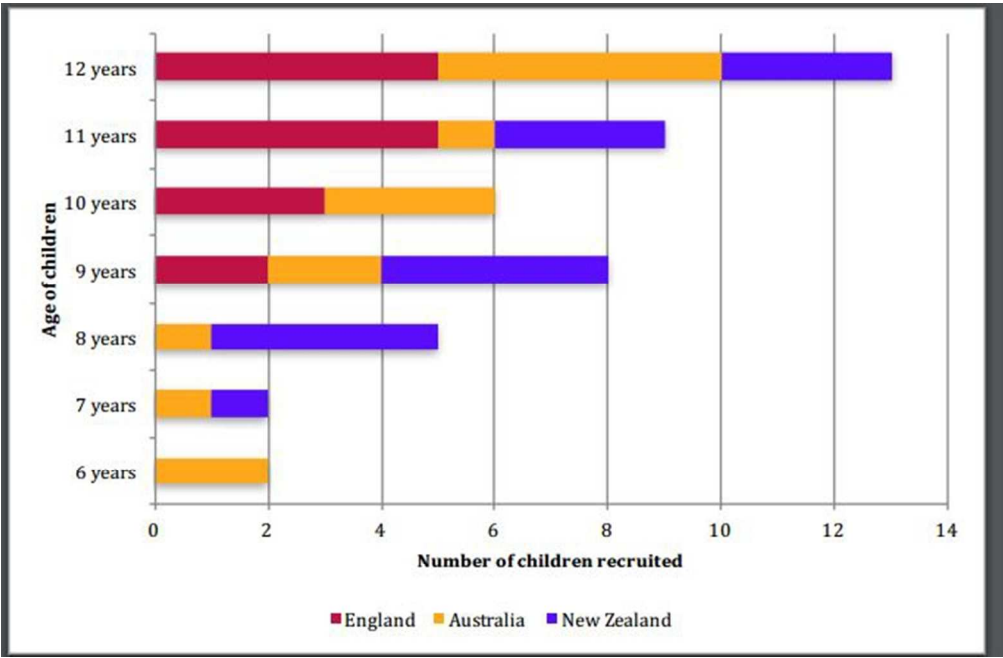


Figure 1: Ages of Children, by country.

180x117mm (96 x 96 DPI)

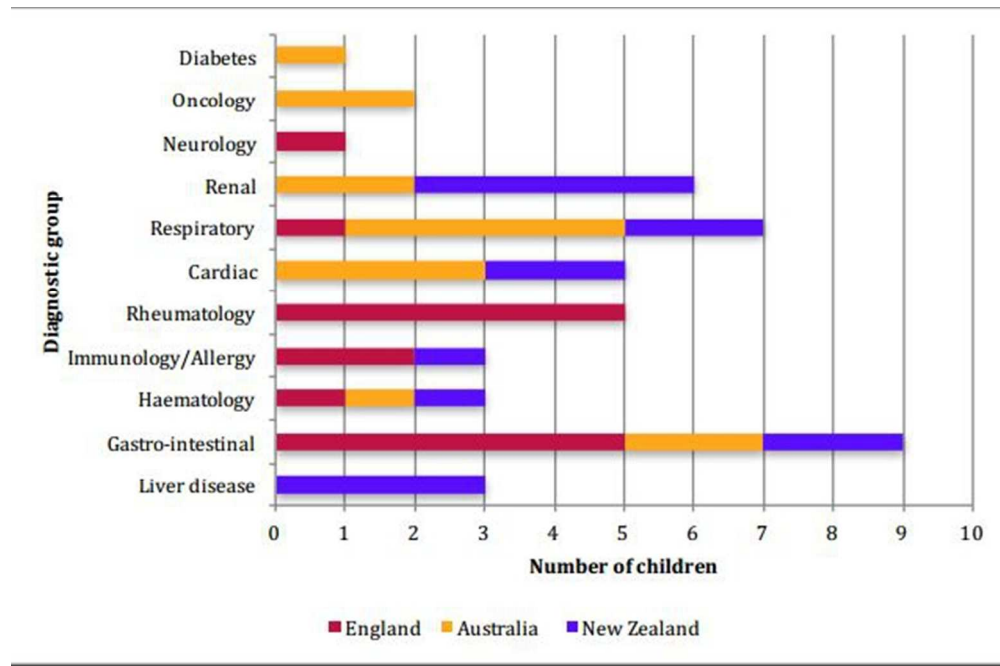


Figure 2: Diagnostic group of children, by country.

169x112mm (96 x 96 DPI)

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Photograph of boy playing

338x254mm (300 x 300 DPI)

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Photograph of medication along with everyday items

390x292mm (300 x 300 DPI)



Photograph of child having treatment in hospital

146x195mm (300 x 300 DPI)